(65)

No. 88-1503

IN THE

Supreme Court of the United States

OCTOBER TERM, 1989

NANCY BETH CRUZAN, BY HER PARENTS AND CO-GUARDIANS, LESTER L. AND JOYCE CRUZAN,

Petitioners,

v.

DIRECTOR OF MISSOURI DEPARTMENT OF HEALTH, AND ADMINISTRATOR OF THE MISSOURI REHABILITATION CENTER AT MT. VERNON,

Respondents,

v.

THAD C. MCCANSE, GUARDIAN AD LITEM,

Respondent,

On Writ of Certiorari to the Missouri Supreme Court

BRIEF OF NATIONAL NURSES FOR LIFE AS AMICUS CURIAE IN SUPPORT OF RESPONDENTS

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EDITOR'S NOTE:

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MOTION FOR LEAVE TO FILE A BRIEF AS AMICUS CURIAE ON BEHALF OF RESPONDENT

Amicus hereby respectfully moves for leave to file a brief amicus curiae in the present case. Requested consent of parties is expected but has not yet been received and filed. When filed, it will make this motion unnecessary.

INTEREST OF AMICUS CURIAE

National Nurses for Life is an organization of nurses who use our professional skills to promote respect for human life. Our state chapters agree with the substance of this brief.

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SUMMARY OF ARGUMENT

Nurses are trained to care, not to kill. Perhaps this is why all 39 nurses at Nancy Cruzan's hospital refused to cooperate in the removal of nutrition and hydration from Nancy. Unconscious people used to be considered to be in a coma. A few years ago, it became obvious that there was a spectrum of unconscious symptoms, from coma to nearly conscious. A term "persistent vegetative state" was coined to describe those between true coma and conscious. But that is still an enormous spread with diverse symptoms. Nancy Cruzan has capabilities which are beyond those defined for persons in the PVS. She can hear and obviously has some cerebral function, but there has not yet been coined a term to describe those like her between the typical PVS with brain stem activity, but no cerebral activity

and consciousness. The definition of nutrition and hydration as medical care has been rejected by all states legislating living will laws. 15 of 40 states explicitly exclude nutrition from the type of care which can be stopped by application of living will laws. All the other states exclude the type of killing sought by petitioners herein by not permitting removal of comfort care, explicitly forbidding euthanasia, or not permitting the living will to take effect until death is imminent. Most states do all three.

ARGUMENT

As a society, Nancy Cruzan scares us. She and others like her remind us of our own vulnerability, fragility, and mortality. We find that frightening. We would prefer to think of her as different from us. But we cannot.

All of us, in some way are disabled. Some disabilities are just more obvious than others: Some of us are disabled from blindness, retardation, paralysis, mental illness or any number of things. Others of us are invisibly disabled from greed, intolerance, pride, apathy, selfishness, etc. Sadly, these invisible disabilities may be the most severe of all.

As nurses, we are sometimes called upon to be the "last friend" of people abandoned by relatives, friends, or even society. We are the ones who care for

those with AIDS, the terminally ill, the severely deformed, the comatose, the drunk, the senile, the criminal, the cantankerous, the deranged, the homeless. We do not change our level of commitment or caring. We are professionals; we do not discriminate.

In court cases involving people like Nancy Cruzan we are often one of the few voices upholding our patients' right to be fed and cared for. Why? Not because we are paid large sums of money for our work. Not because we are ignorant. Not because, as one witness put it, we are "too emotionally involved" with our patients.

We speak out because we are professionals. We speak out because justice demands it. We speak out because our patients cannot.

By caring for these people whose very existence seems to trouble society, we nurses are affirming the humanity of us all.

Nursing The role of nurses is not only to provide care for a patient but also to be an advocate for that patient. The amount of time spent with patients, the intimacy of the nurse-patient relationship, and the emphasis nursing places on meeting the physical and emotional needs of patients and their families places nurses in a unique position to contribute to discussions of health care ethics and public policy.

As patient advocates the best interests of the patient is our foremost consideration. The judgement of the doctor, the policies of the health care institutions, and the wishes of the family can-

not take precedence over the rights of the patients.

While we agree that the question of <u>who</u> should make health care decisions when a patient is unable to speak for himself is an important question, the larger question should be <u>what</u> decision is being made. We strongly believe that "health care" decisions to cause the death of a patient are illegitimate no matter who is making the decision. Therefore we conclude that it is not ethically permissible to withhold or withdraw food and water from people in the so-called "persistent vegetative state" or from other categories of seriously disabled by nonterminal persons.

We feel such actions constitute <u>abandonment</u> of the patient. Even when cure is not possible we still have a responsibility to care for the patient.

<u>Justice</u> requires that we extend the basic necessities of life to all persons, regardless of race, age, socioeconomic status, disabilities, etc. To deny these necessities to some (rapidly expanding) groups of people based on their degree of disability is discrimination. Causing death by starvation and dehydration should not be more morally palatable simply because it occurs (for now) in a medically sanitized setting.

Withholding nutrition and hydration from non-dying, disabled people does not "allow" these people to die, it <u>forces</u> them to die. Starvation and dehydration is a slow, painful, and disfiguring process. For example, in 1988 Marcia Gray, a Rhode Island woman, reportedly lost 50 lbs. and required medication to control seizures during the 15 days it took her to die following court-sanction removal

of her feeding tube. Death by starvation and dehydration is hardly "death with dignity." The main witnesses to these kinds of deaths are nurses. The negative effects, both personally and professionally, of participation in these kinds of deaths may mandate the institution of special wards to insulate the stress from other patients, staff, and visitors.

Furthermore, we deplore the recent trend in some court cases to force institutions and health care providers by court order to remove feedings in violation of conscience rights. If this trend continues, health care professionals will be reduced to mere technicians dispensing a consumer service. Usual standards of professional accountability and judgement will be rendered inoperative in these cases. The effect on the art and science of health care will be devastating.

The perceived economic imperative of rationing health care will almost certainly expand the pool of vulnerable people. Quality of life criteria could even come to include socioeconomic status, family support, and the willingness of society to offer services. We have already seen this in the current Johnson case in Oklahoma. (In that case an actual formula was devised to decide which babies with spinal bifida would receive aggressive treatment. The formula was even published in a pediatric journal: QL=NE(H=S): quality of life equals natural endowments times the expected contribution from the home and society. Using this equation could logically mean that a perfectly healthy but deprived child could come up with a low score on quality of life. For example QL=100(0+0)=0.)

Discrimination Consciously or unconsciously many of us are accepting the removal of feedings because of personal fears of becoming disabled or being a "burden" on loved ones. Most healthy people cannot imagine what it is like and assume that life would be devoid of comfort or happiness with even a partial disability. However, our natural fear of becoming disabled and "losing control" must not allow us to discriminate against people with disabilities. Quality of life must not take precedence over the sanctity of life.

Disabilities can range from mild to severe. It is dangerous to arbitrarily choose one point for non-treatment without risking the lives of people with lesser disabilities. As nurses we care for people some of whom can be returned to normal health, some of whom we cannot

save, and some of whom are left with impairments. Our commitment to caring for each of these groups is the same.

Too, as nurses, we have been impressed and inspired by our patients and their relatives. The will to live, ability to accept hardships, and love of life we see in these people teaches us much and makes our work very rewarding. It is sad when we hear that people like Nancy Cruzan lead a "degrading" life by having others bathe, toilet, and feed her. We believe that our care is not degrading but rather an act of love.

More and more we are encountering an attitude in society that no one should be e a burden on anyone else. However, we must realize that total independence is a myth; the reality is <u>interdependence</u>. All of us are dependent on each other: we need farmers and truck drivers to provide

us food. We need builders to shelter us, etc.

Also, at some point in our lives, we are all "burdensome." All of us begin life as helpless babies totally dependent on others. Illness, injury, old age, even the stresses of being a teenager can make us burdens on our families or society.

As we all know, too, it is a humbling experience to require or to ask for help. But both giving and receiving help has its own rewards and strengthens our commitment to each other. The measure of our humanity and our civilization is how we take care of one another, particularly the weakest and most vulnerable among us.

To deny feedings to non-dying, disabled people like Nancy Cruzan will have many adverse repercussions: it would have a discouraging effect on other peo-

ple with disabilities, their families, and caregivers by discounting their efforts. It could lead to economic coercion by leading to withdrawal of insurance payments. It could subtly increase other discrimination against the disabled and promote the myth that the disabled are burdens. A person's limitations do not decrease a person's humanity or worth.

To sanction the denying of feedings could lead to lawsuits against families and caregivers who follow their consciences. It could lead to further shortages of nurses who, by being the main witnesses to these kinds of deaths, might leave the profession or never enter it. It could lead to the destruction of trust between nurse and patient because the nurse (and doctor) would assume a dual role as killer/caregiver. The pa-

tient might be reluctant to discuss negative or ambivalent feelings for fear that it might influence a decision that his or her quality of life was not high enough. It could produce a deadening effect on doctors and nurses in relating to commitment to patients and respect for life. Rationalizing active euthanasia like injections would become easier.

Sanctioning denial of feedings could lead to more lawsuits like Nancy Farnum's (*Farnum v Crista*, Superior Court of Washington for King County – Farnum, who previously had a good record, was fired for refusing to withdraw a patient's feeding tube when the doctor who wished to kill the patient ordered her to do so) – as other nurses who refuse to participate are fired, encouraged to resign, or have other sanctions imposed by health care facilities. If sanctioned, it would

be impossible to limit denial of feedings to institutions and what used to be considered abuse or homicide in the home setting could be socially or legally sanctioned. If feedings are denied, it could make it difficult to enforce *any* mandatory minimum care.

Tube Feedings We recognize that it is ethically permissible to remove treatments or care which is useless or burdensome to the patient. However, in deciding what treatment or care can be ethically withdrawn, it is important that the treatment itself be judged, not the "quality" of the person's life. We should not deliberately cause death and then disingenuously claim death came "naturally."

Feedings whether by tube or mouth can rarely be considered either useless or burdensome unless, for example, a per-

son is imminently dying. In general, supplying food through a feeding tube costs less and is usually less troublesome to provide than a prepared meal. Most people tolerate this form of feeding quite well with no pain or discomfort. Discomfort or problems that do occur are usually manageable. For many people attempts at oral feedings would be far more burdensome or even dangerous. For example, many people in nursing homes receive tube feedings for convenience reasons or because the ability to swallow is partially impaired.

The new trend of calling tube feedings useless or "artificial" is problematic. The purpose of tube feedings is to maintain the nutritional status of a person. Tube feedings do not treat illnesses. Tube feedings cannot cure brain damage. To call tube feedings "useless"

is to ignore the purpose for which they are intended.

To call tube feedings "assisted feedings" rather than "artificial feedings" may be more accurate particularly in light of the fact that one expert witness in the Nancy Cruzan case testified that he would consider spoon-feeding Nancy "medical treatment."

To attempt to call tube feedings "artificial" also raises other questions: if feedings can be artificial could not also clothing or maintenance of room temperature also be considered artificial? Is bottle-feeding a baby artificial? If tube feedings consist of nothing more than blenderized food would they then be considered natural? With so much of our nation's food supply artificially processed could not our regular food be considered artificial? Is the tube itself

more analogous to a machine or a simple soda straw? Why would an "artificial" medical treatment such as a morphine drip for pain be considered necessary for prevention of discomfort while feedings would not? Why is bathing or turning patients who have their feeding tubes removed considered mandatory?

Tube feedings have been in existence since the 19th century according to one source (see enclosed articles). In recent years there have been great innovations in tube feedings. Tubes can now be inserted at the bedside. In one technique a guide wire is passed through the mouth, down the esophagus and out the stomach so a gastrostomy tube can be placed. Gastrostomy buttons (small mushroom-shaped devices which lie flat on the abdomen) can be inserted and even changed or reinserted by a conscious patient.

Tube feedings can now be given either intermittently or continuously to minimize problems.

We believe the attempts at practical or ethical justifications for removal of feedings will mislead people to believe that causing death by omission is different fundamentally from active euthanasia by lethal injection, overdose, etc. Indeed it is ironic that both we and pro-euthanasia groups agree that there is no real difference between causing death by starvation and dehydration or causing death by giving a lethal injection or other active means. Some pro-euthanasia groups logically consider lethal injections more "humane" since death by starvation and dehydration is a slow, painful, and disfiguring process.

Persistent Vegetative State

This is an unfortunate and imprecise term

used to describe people who are severely brain-injured but not dying or brain-dead. The diagnosis of PVS is based on an assumption that there is a total lack of upper brain function. As the American Medical Association admits there are no tests to determine PVS. The diagnosis is based on subjective observation over an unspecified period of time ranging from 3 days in the California Herbert case to years as in the Nancy Cruzan case. Also, as in the Nancy Cruzan case, medical experts themselves often disagree about the diagnosis of PVS. Also, though often termed "irreversible" there have been many cases of people regaining consciousness. Witness the Carrie Coons case in April, 1989. Mrs. Coons, an 86 year old woman from New York, was judged to be in an irreversible vegetative state and feedings were ordered withdrawn.

However, just before the court order was to take effect, Mrs. Coons regained consciousness and began eating. When asked whether she would have wanted her feeding tube removed (as relatives had claimed) she expressed uncertainty and also said, "I didn't know anyone cared." (Mrs. Coons also illustrates the problems of "substituted judgement" and of media articles claiming so-and-so "wins the right to die." As nurses we are concerned that usual standards of informed consent are being abandoned in favor of casual prior conversations, vague living wills, and arbitrary decisions by guardians. Why, also, must the right to refuse treatment or care be given automatic preference over the right to consent? As nurses we are aware that families, when asked to make decisions for incompetent people, are very vulnerable, medically unin-

formed, and under great stress. The biases of physicians can be unduly influential under such circumstances.)

We must also face the fact that removing feedings from people in so-called PVS does not "allow" them to die, it <u>forces</u> them to die.

The term "vegetative" itself is dehumanizing. As nurses we know we are not caring for carrots or radishes. History teaches us both the power and the folly of using dehumanizing terminology: In Nazi Germany Jews were termed "lice" or "vermin." In our own country blacks were called "slaves" and "property." Today we see unborn babies called "products of conception" and "uterine contents."

As nurses, too, we are taught to always assume a patient can hear. Many of us have been stunned when formerly comatose patients can recount bedside con-

versations. One of our members recounts a case where a severely injured teenager in a deep coma later refused to respond to a neurosurgeon who the teenager remembered hearing predicting that the boy would be a vegetable if he lived through the night. Yet now we nurses are called upon to accept without question, based on no valid scientific evidence and contrary to hundreds of recoveries from the state called upper brain "death," that there are absolutely no mental functions in certain patients.

The fact that many, if not most patients in comas or so-called "vegetative states" do not regain consciousness does not mean these people have lost their humanness, personhood, or ability to hear or feel. If failure to recover (to what is considered by some to be an acceptable level) becomes the standard for feeding,

then old age, paralysis, etc could also be considered as meeting the criteria.

How far is it from there to Hadamar?

COMMENTS ON THE AMERICAN NURSES ASSOCIATION BRIEF

p3 The American Nurses Association numbers less than ten percent of American Nurses, and cannot presume to speak for the other more than 90%. The ANA could only get two of its fifty state affiliates to join its brief.

p4 We strongly deny tension between the Missouri Supreme Court decision and the majority of nurses. How can anyone make that claim when all 39 nurses at Nancy's hospital have refused to participate in the removal of nutrition and hydration from Nancy? [See transcript page 619, lines 11-18, Appendix A5 infra.]

p4 The right to starve a PVS patient has been rejected by all states and is

illegal under the laws of all states.

p4 The right to decide for one's self whether to submit to medical treatment cannot be at issue here, since nobody claims Nancy Cruzan will be making any decision. We believe most nurses would prefer not to kill a patient by starvation, and we disagree that not killing Nancy violates ethics or the nurse's role as patient advocate.

p8 If this Court reverses, the tube will not be withdrawn. The difference will be that nutrition and hydration will be cut off for the purpose of killing Nancy, a risk worse than continuing feeding.

We submit that the question herein is whether this Court will find an unenumerated right to kill in the US Constitution sufficient to overturn as unconstitutional the applicable laws of every state.

IS THE RIGHT TO KILL UNWANTED PATIENTS BY REMOVING NUTRITION AND HYDRATION A FUNDAMENTAL LONG STANDING RIGHT?

This claim is made in many briefs supporting appellants. At first thought, it seems difficult to conceive of a right that nobody even suggested existed until very recently as fundamental and of long standing. We know what the amici think of this alleged right, but perhaps we should determine what America thinks of it. How many states have enacted this so called fundamental right into law? Exactly none.

How many states of the forty with living will laws explicitly mention nutrition and hydration and forbid their removal even when the rest of the living will law is enforceable? Fifteen.[37.5%]

How many states forbid the relief sought herein by requiring comfort care? Thirty one.[77.5%]

Cutting off Nancy Cruzan's nutrition and hydration would be done for only one purpose, to kill her. How many State living will laws explicitly forbid euthanasia? Thirty three.[[82.5%]

Nancy is not dying. How many states forbid the execution of a living will law until death is imminent? Thirty six.[90%]

If the Court reverses, the following changes will probably follow, either explicitly or in lower court opinions later based on the present case:

1] The terms medical care and medical treatment will then include assisted feeding, including nutrition and/or hydration of non terminal patients, by tube or spoon which are equated with medical care.

Change

At this time zero states (none) have defined medical care or treatment to

include assisted feeding in any form which can be removed. Tennessee states [32-11-104] that they are medical care, but in the same section states: "Provided, however, that in no case shall this section be interpreted to allow the withholding of simple nourishment or fluids so as to condone death by starvation or dehydration." If this Court reverses, perhaps in all states, all types of assisted feeding, even spoon feeding will be medical care under the US Constitution, which "medical care" can be removed for the purpose of killing.

At this time at least 15 states of the states having living will legislation have specifically excluded nutrition and /or hydration from the type of medical care that can be omitted pursuant to living will legislation. All the rest have provisions preventing the omission

of nutrition and hydration from non terminal patients at least by implication.

States specifically differentiating nutrition and hydration from medical care and treatment and specifically forbidding the removal of nutrition even when the provisions of the living will law permit the removal of medical care, include: (listing states in alphabetical order, followed by the appropriate code section):

AZ PHS 36-3202 C; CONN 19a-570 (1) 44 765.03 (3) (b); GA H 31-32-2 (5) (A); HI H 327 D2; IN HH 16-18-11-4 2; MAINE HS 22 2921 4; MD HG 5-605 1; MISSOURI TE 459.010 3; OK PHS 3102 4; OR PRT 97.050 3; SC H 44-77- 20 2;TN W 32-11-101 9 (artificial or forced feeding is medical care, but cannot be withdrawn); UT UPC 75-2-1103 6b; WI PH 154.01 5b; WY

35-22-101 iii;

2] Involuntary euthanasia and mercy killing will be defined as US Constitutional Rights. It would follow that voluntary euthanasia and mercy killing would also be defined as US Constitutional Rights.

Change

At this time at least 33 states specifically and explicitly forbid euthanasia and mercy killing in their living will statutes.

AL H,MH,EC 22-88A-10; AK HS 18.12.080 (f); AR 20-17-210 (g); AZ PHS 36-3209; CA HS 7195; CO 15-18-112 (1); DC 6-2430; FL 44 765.11; GA H 31-32-11 (b); HI H 327D-13; IL PROBATE 110 1/2 709 f; IN HH 16-8-11-20; IO PH 144A.11 6; KS PH 65-28, 109; LA PHS 40: 1299.58.10A; MAINE HS 22 2929 6; MD HG 5-610 3; MN PR 145 B.14; MS 41-41-117 2; MISSOURI TE 459.055 5; MT HS

50-9-205 6; NV HS 449.670; NH PH 137-H:13; NC MAC 90-320 b; OK PHS 3111; OR PRT 97.085 1; SC H 44-77-130; TX 71 HP 4590h 10; UT UPC 75-2-1118; VA PO 54.1-2990; WA PHS 70.122.100; WV PH 16-30-10; WI PH 154.11 6; WY 35-22-109;

3] Removal of comfort care would be a US Constitutional Right.

At this time at least 31 states specifically forbid removal of comfort care in their living will statutes. By implication, it would be illegal to starve Nancy Cruzan under the laws of these states because dying of thirst or starvation are uncomfortable. These states include:

AL H,MH,EC 22-8A-3 (3); AK HS 18.12.010 (c); AR 29-17-202 (b); AZ PHS 36-3202; COL 15-18-104(3b); CONN 19a-573; DE 16 2501 (d); DC 6-2421 (3) FL 44 765.03 (3)(b); GA H 31-32-2 (5) (B) (pain); HI H

327D-2; ID 39-4503 (3) pain; IL PROBATE 110 1/2 702 d; IN HH 16-8-11-4 2; IO PH 144A.2 5b KS PH 65-28,102c; LA PHS 1299.58.2 4; MAINE HS 22 2925 2; MN PR 145 B.13 1; MD HG 5-602 c 1; MISSOURI TE 459.010 3; MT HS 50-9-202 2; NV HS 449.58; NH PH 137-H:2 III, 3; OR PRT 97.0503; SC H 44-77-20 2; TN W 32-11-103 6; TX 71 HP 4590h 4; UT UPC 75-2-1103 6b; VA PO 54.1-1982; WV PH 16-30-2 3; WY 35-22-101 iii;

4] Removal of care when death is not imminent would be a US Constitutional Right.

At this time at least the following 36 states specifically forbid in their living will laws removal of medical care when death is not imminent or unless the medical care would only prolong dying.

AL H,MH,EC 22-8A-4 (c); AK HS 18.12.010; AR 20-17-201 (9) AZ PHS

36-3202; CA HS 7187 (c); CO 15-18-103 (7), 1989 revision [would serve only to prolong dying] CONN 19a-570 (3) DE 16 2501 (d) DC 6-2421 (7); FL 44 765 (6) GA H 31-32-2 (5); HI H 327 D-4; ID 39-4504; IL PROBATE 110 1/2 702 h; IN HH 16-8-11-9 2; IO PH 144A.2 8; KS PH 65-28,102c; LA PHS 40:1299.58.2 4 & 8; MAINE HS 22 2921 8; MD HG 5-502 g; MN PR 145 B.01 8; MS 41-41-107, -113; MISSOURI TE 459.010 3, 6; MT HS 50-9-102 4; NV HS 449.610; NH PH 137-H:2 VI; NC MAC 90-321 (TERMINAL CONDITION); OK PHS 3102 4; OR PRT 97.050 3, 6; SC H 44-77-20 2, 44-77-50; TN W 32-11-103 9; TX 71HP 4590h 4; UT UPC 75-2-1103 6a; VA PO 54.1-2982; WA PHS 70.122.020 4; WI PH 154.01 8; WY 35-22-101 vi.

IS NANCY EVEN PVS?

PVS is a catchall term which can, depending on the definition used, sweep

up everyone who is neither conscious nor in a coma. The AMA, President's Commission and others advocating the killing of the PVS by cutting off nutrition and hydration justify the killing by claiming it excludes those with cerebral function. Then, in application, they broaden the scope of the term PVS to include those like Nancy who have some cerebral function. It is the slippery slope right before our eyes. [Please see appendix of selected trial testimony infra.]

CONCLUSION

The Court should not legislate a right to kill the PVS. If it wishes to do so, however, it should at least wait until a case comes along involving a soon to be decedent who is indisputably PVS

Respectfully submitted,

ROBERT L SASSONE, Attorney for amicus

APPENDIX, TRANSCRIPT EXCERPTS

We feel the following parts of the transcript ar relevant:

T103L7, CAT Scan failed to reveal abnormalities.

T106L16, Nancy is not dead.

T107L10, 7-14 days to starve.

T108L8-14, Dr had never heard of anyone coming out of PVS, if he had, it might have changed his opinion.

T109,L1-9 Nancy has improved, pupils dilate, has facial expressions, responds to pain or stimuli.

T111 L1 Nancy was fed orally, safer to feed her through tube.

T114,L15 Some Drs disagree about removing nutrition and hydration

T126 PVS defined, no consciousness, no thinking, no feeling, no voluntary interaction with environment, [but literature indicates some PVS have done

all these things.]

T137L13 Nancy smiled at valentine.

T140L20 Nancy looks toward sounds.

T142L10 Nancy startled by sounds.

T145L15 Nancy responded to pain, flexed and grimaced.

T286L3 Nancy followed objects with eyes.

L11 Nancy eating soft food.

L18-18 Nancy holding head up for 30 seconds, looking around, responding to olfactory & auditory stimuli, tracking and following a command.

T290 rehab report, sitting up toleration fairly good.

T311 L17 Hospital refused to starve Nancy.

T313L3 Literature shows 5000-10,000 PVS in US.

T317L11 menstruates.

L20 Nancy startles to sounds and grimaces to pain.

T318 L18 Nancy's eyes track better than most PVS.

T320L6 Nancy tries to withdraw from painful stimulus.

T321L4 Treating Dr could not honor request to cut off nutrition & hydration.

T325 L3 Nancy is most responsive of his PVS patients, only of his PVS to sneeze.

T332 L12 Nancy's EEG normal, that caused Dr trouble.

T334L3 Nancy occasionally in chair.

T338 L7 Dr not convinced one way or another of how much awareness or how much experience Nancy actually receives.

T373 Nancy opens eyes if someone bumps something

T374 L10 Nancy had tears when family left, and when valentine read.

T378 L18 Charge nurse trained to save lives, not enhance death, does not want to assist in withdrawing food & water.

T453 L5-7, Couple insurance policies with parents as beneficiary.

NURSES

T594L20 Nancy looks toward your voice, definitely responds to sound 75% of time.[T595]

T595,L23 Nancy reacts only to some voices and has cried. [the previous month T596] and has cried other times.

T599L4 Nancy holds hand and pulls

L24 Nancy grimaces and moans when pain, definitely smiles all over.

T601 L17 Nancy sits in chair three hours daily.

T602 Nancy does not like hair washed and lifts her head., down to chest, Nancy can get scared.

T603, If talking to Nancy and touch her, if she knows touch is coming, she does not tense up, but does tense up if surprised. Nancy tenses to loud noises.

T606 L13 Speak to Nancy & she looks at you.

T607 L2 Nancy understands what you are saying at times.

T 608, L14 Reactions were not present initially.

T609 L1 opposes starvation.

T614 L19 Nothing in Nancy's care that requires skilled nursing,

L25 Nancy requires least skill of any patient on floor

T615 L23 Nancy could be cared for at home

T616 L10 Family or nursing home could care for Nancy

T617 L2 Nancy opens eyes if her name is spoken

T618 L18 Tylenol relieves Nancy's moaning & groaning

T619 L11 Cannot participate in withdrawal of nutrition & hydration. Nobody of 39 people on nursing staff will participate

in the withdrawal.

T622 L19 Other families have cared for people that were in Nancy's condition.

T623 L7 Nancy opened eyes in response to her name three days ago.

T641 L25, Nancy does respond.

T643 L6 Nancy certainly can hear.

T644 L21 Nancy has cried 5 times past 6 months.

T646 L6 Nancy differentiates between staff members.

L22 Staff has volunteered they cannot handle her starving & dehydrate to death.

T650 L6 Nancy snickered & smiled at an appropriate time.

T653 L15 Nancy tries to move lips & talk at appropriate times

T654 L25 When Nancy identifies where sound comes from, she turns head towards that sound.

T657 L22 Saw Nancy cry about 5 times last six months when people left room.

T659 L11 Nancy responds the most to people she is most familiar with.

T663 L3 Sometimes Nancy has a more relaxed happier expression.

L8 Nancy moves her mouth a lot.

T664 L7 Dr not there much, Nancy does not react with strangers or those seldom there.

T665 L15 Nurses respond when Nancy grimaces & shows facial expression of pain.

T666 L21 Morally unethical to remove Nancy's nutrition.

T668 L3 Never thought giving food & water was treatment.

T670 L2 No hospital ethics committee.

T671 L5 Easier to live with Nancy 15 years than watch her die of starvation & dehydration.

L8 Has watched someone die of starvation or dehydration.

REHAB DR ISSAC

T675 L17 Number of head injured has grown, but we know very little about management & prognosis. Data increasing more rapidly & there now is a journal.

T677 L7 Some of PVS and a fairly good percentage of them will move from one stage to another, will improve, but lack of staff & funds.

L21 We do not know what is possible insofar as rehabilitation of persons in PVS for longer period.

T679 L12 We really don't know what her possibilities were.

L20 Nancy hears & perceives what's going from the environment.

T680 L3 Nancy might have been able to learn to feed self if left in rehab longer.

L7 Not possible to know how much Nancy is aware of or experiencing at present. Some areas she seems to perceive what is going on. Auditory function fairly consistent.

L18 Gradual improvement even though she has been very isolated and there has been kind of a determined effort to keep her in coma for a long time.

T681L7 We can't know due to defect in our technology.

T683 Youngblood in state similar to Nancy for over a year and has come out at the hospital, no longer PVS.

T684 L3 Cannot say Nancy cannot improve.

L9 Nothing complex about Nancy's care, could be done at home

L19 No real risks to Nancy's care, not much trouble with tube.

T685 Nancy experiences Pain & discomfort every time there is painful stimulus.

L13 Nancy is aware that she hurts & can repeat it & message gets through to her.

T689 Not appropriate to remove tube which is basic human care, not medical care in any sense, unethical to remove tube.

T690 L13 Certain Nancy would feel stomach cramps from pain.

T696 L12 Nancy is not in PVS at this time, she is better off than PVS because she can respond to her environment.

T702 L10 Nancy has some cognitive function now.

T704 L4 Nancy hears & reacts to what she hears, follows voices in the room & reacts to people who have been there.

T706 L5 Nancy has not been given much opportunity to develop.

T709 Agrees with AAN definition of PVS, but Nancy is not PVS, she can do more, ie auditory.

T712 L21 Disagrees with Davis assessment of PVS.

T716 L24 Nancy feels pain.

T717 L10 Neurologist examined Nancy under conditions where he couldn't tell if she was PVS.

T720 L16 She understands why Drs say in theory patients incompatible with consciousness, but disagrees based on her experience.

T729 L13 Removing feeding tube will be painful to Nancy.

T735 L18 Ethically it is killing.

T744 L13 One cannot be sure about how much Nancy experiences or is aware of.

DR DEXTER, Chairman Dept Neurology, U of MO

T751 L2 Nancy orients to sound.

T754 Nancy has upper brain function.

T755 Nancy fixed on his face when he moved it. Nancy does more than fix on

sounds, she fixes on objects. Nancy does have cortical function if the parietal & occipital lobes.

T756 He believes the nurses, several say same thing. PVS is everything between coma & consciousness. A routine neurological examination will not test for PVS. Neurology is going to change.

T757 Nancy orients & maintains the orientation.

T758 Nancy's turning toward sound is cortical function.

T759 Nancy feels pain above & beyond the reflex level since she not only closes her eye in the usual response, but she also frowns down.

T760 Nancy attends, focuses on his face & follows it if moved.

T761 Trial court is hung up on definition & president's commission.

T762 CT Scan & shrunk brain not relevant.

Many with less brain can bowl, are in school, etc. Pet Scan still experimental, should not be relied on by court.

T763 Nancy does receive sensory input.

T764 Nancy is not PVS since she is sensitive to environment & responds to it.

T765 Nancy is absolutely alive. Question is are you going to kill her.

T766 We do not know if Nancy can improve.

T769 Criticizes President's Commission confusion of unconscious patients & PVS

T770 Everyone has a right to food & water.

T771 Nancy is not getting medical car

T775 Very dangerous to society to withhold food & water from Nancy, we do not have adequate data re outcome.

T793 Distinguishes (AMA) guidelines, since Nancy is not comatose.

T796 Distinguishes Pres.Commission.

NO 88-1503
IN THE SUPREME COURT OF THE UNITED STATES
OCTOBER TERM, 1989

NANCY BETH CRUZAN, BY HER PARENTS AND CO-GUARDIANS, LESTER L AND JOYCE CRUZAN
Petitioners,

v.

DIRECTOR OF MISSOURI DEPARTMENT OF HEALTH, AND ADMINISTRATOR OF THE MISSOURI REHABILITATION CENTER AT MT. VERNON,
Respondents,

v.

THAD C. McCANSE, GUARDIAN AD LITEM,
Respondent.

Affidavit of mailing of amicus brief copies, Rule 28.2

State of California }ss.
City of Santa Ana, County of Orange }

Robert L Sassone, being first duly sworn on his oath deposes and says:

Robert L Sassone is a member of the bar of the United States Supreme Court admitted October 26, 1971. To his knowledge, on October 11, 1989, within the particular time and permitted time for serving of said amicus brief pursuant to Rule 28.2, he deposited in the United States Mailbox at Santa Ana, CA 92701 pursuant to Rule 28.2 with first class postage prepaid 40 copies of the attached amicus brief in the present case properly addressed to the Clerk of the United States Supreme Court and three copies of said amicus brief to each party addressed as follows:

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_____

ROBERT L SASSONE, Affiant,

Subscribed and sworn to before me on
October 11, 1989,

_____

Lawrence D Sassone, Notary Public